

Dear PHIN Conference Attendees:

Welcome to the First Public Health Information Network Stakeholders' Conference. We hope you will find the conference informative and thought-provoking. At this conference you will learn what has been done and what is planned for the Public Health Information Network. This is your opportunity to advise CDC and others working on PHIN about your experiences and information needs.

We titled this document "A Work In Progress" because PHIN is in the very beginning stages of development. While a lot of work has been done to define and plan for the PHIN, it remains a vision. We have summarized the best information that we have at this point so that you might understand more about the current definitions and building blocks for the PHIN. The process of developing this document gave us a better understanding of where we need to go in the future. We hope that this document and the other resources you receive at this meeting will help you do the same.

The goal of working with public and private sector partners at the Federal, state, and local levels to develop an interoperable network of health-related information systems is commendable. It will take sustained resources and dedication to partnerships at many levels to make the PHIN work. We hope that you will remain an active participant in developing the PHIN. We look forward to working with you to make PHIN a success.

— The PHIN Partners

Acknowledgements

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What is PHIN?

The Public Health Information Network (PHIN) is an electronic system that supports monitoring of the public's health. PHIN will detect health problems, analyze accumulated data, create useful information, communicate alerts as needed, and inform appropriate responses. The overall vision for the PHIN is to be the information network that integrates public health partners across the nation. PHIN will have dual functionality by providing a foundation for routine public health activities and by enhancing bioterrorism detection and response.

PHIN will be a live, secure, Internet-based network for exchanging comparable critical health information between all levels of public health (local, state, and federal), and other critical information systems. A key PHIN building block is the adoption of IT standards and specifications so that public health and its partners can be connected and data can be readily shared and analyzed.

The majority of health issues impacting the public are multi-faceted (genetic, environmental, behavioral, etc.) and require data from multiple sources to be analyzed. PHIN adds a new dimension to public health practice by providing a network that supports the analysis of multiple data sets that can be turned into meaningful information. In addition, PHIN will reach beyond public health professionals and communicate this information to the public and the healthcare workforce. PHIN will

not only provide a “pulse” on the public’s health, it also has the potential to improve the public’s health.

PHIN Background

Public health and terrorism preparedness require many organizations to work together and exchange information. The goal of the PHIN is to get high quality, consistent information to decision makers quickly, across local and state lines, and between health care systems and public health organizations.

PHIN is an effort to create a fully interoperable network for public health information that is inclusive. Implementation encompasses the development and use of information systems addressing surveillance, alerts and communications, laboratory and clinical data management in both the public and private sectors, and epidemiologic case investigation and management.

The vision of the PHIN is to transform public health by electronically enabling: real-time data flow, computer assisted analysis, decision support, professional collaboration, and rapid dissemination of information to the public health community, the clinical care community, and the public.

CDC and its partners have implemented technology initiatives that demonstrate the value of public health information technology. The “building blocks” for PHIN include systems and networks already familiar to the states: the Health Alert Network (HAN), the National

Electronic Disease Surveillance System (NEDSS), the Laboratory Response Network (LRN), and the Epidemic Information Exchange (EPI-X).

As with any network, the use of a common data language and interoperable architecture are keys to success. CDC’s goal is to make PHIN an interoperable network that integrates public health systems and functions while using industry standards to work with other networks/systems. For public health participants, it is important to promote industry standard data models, vocabularies, and messages.

PHIN Building Blocks

Surveillance Monitoring and Tracking Systems

Surveillance monitoring and tracking systems are the foundation of public health disease control efforts. Surveillance from a public health point of view started out from individual disease surveillance in the 1950s, later in 1963 was broadened into population surveillance, and in 1986 was defined by CDC as

The ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know.

Surveillance systems have various interrelated functions that serve to establish baseline data, evaluate temporal

trends, identify and document outbreaks, evaluate disease interventions, set disease control priorities, and study the natural history of disease.

For centuries, people have been monitoring and tracking diseases. It was in the late 1800s that the United States, through congressional appropriation, collected and published reports on notifiable diseases, which included cholera, smallpox, plague, and yellow fever. In the early 1900s, Congress enacted a law directing the Surgeon General to provide forms for the collection and compilation of data and for the publication of reports at the national level. The number of nationally notifiable diseases grew from four to over 50 diseases, and as technology improves telecommunications, from telegraphic reporting to electronic reporting.

❑ National Electronic Telecommunications System for Surveillance (NETSS)

In 1984, CDC, in cooperation with the CSTE and epidemiologists in six states began testing the Epidemiologic Surveillance Project. The project's goal was to demonstrate the effectiveness of computer transmission of public health surveillance data between state health departments and CDC. Computer programs were created that used existing disease surveillance systems to transmit data to CDC on cases of all nationally notifiable diseases. By 1985, the system became a full interactive computer-based disease reporting system, and by 1989, all 50 states had begun participating in the reporting system. The Epidemiologic Surveillance Project was then renamed the National Electronic Telecommunications System for Surveillance

(NETSS) to reflect its national scope. (Source: <http://www.cdc.gov/epo/dphsi/netss.htm>) In addition to NETSS, specific infectious disease programs, such as Tuberculosis and HIV/AIDs, had developed their own surveillance systems. It became clear that one comprehensive disease surveillance system was needed and the National Electronic Disease Surveillance System (NEDSS) project was begun in 1999.

❑ National Electronic Disease Surveillance System (NEDSS)

The National Electronic Disease Surveillance System is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated and interoperable surveillance systems at local, state and federal levels. A primary goal of NEDSS is the ongoing, automatic capture and analysis of data that are already available electronically.

The major benefits of NEDSS include a person-based approach, so that information can be tracked in a longitudinal manner. Also, NEDSS receives and transmits real-time electronic messages (e.g. lab reports on notifiable diseases). As a result, NEDSS can quickly send information, more cases will be tracked, and there is less burden in sending and entering information.

NEDSS is based on the following principles:

- Utilization of industry standards
- Reliance on off-the-shelf software

- Internet-based secure transmission of data
- A common “look and feel” for all systems
- Common reporting requirements
- No requirement to use specific software

NEDSS is designed to address the limitations of current surveillance systems which include:

- Multiple incompatible disease specific systems
- Incomplete and delayed data
- Burden on health care system to report disease
- Overwhelming volume of data to be managed by health departments
- Lack of state-of-the-art information technology

The mission is to design and implement seamless surveillance and information systems that take advantage of the best information and surveillance technology, and serve the following needs at the local, state, and national levels:

- Monitor and assess disease trends
- Guide prevention and intervention programs
- Inform public health policy and policy makers
- Identify issues needing public health research
- Provide information for community and program planning
- Protect confidentiality while providing information to those who need to know

NEDSS system architecture is designed to integrate and replace several current CDC surveillance systems, including the National Electronic Telecommunications

System for Surveillance (NETSS), the HIV/AIDS reporting system, the vaccine preventable diseases and systems for tuberculosis and other infectious diseases. The NEDSS Base System, which uses NEDSS standards, is developed by an experienced software engineering company, Computer Sciences Corporation (CSC), in consultation with the CDC and state partners.

For more information on NEDSS, visit the NEDSS Web site at <http://www.cdc.gov/nedss/>.

□ National Healthcare Safety Network (NHSN)

Traditionally, clinical sector IT systems have not been standards based or interoperable. Surveillance systems in clinical settings have taken advantage of the progress of information technology, thus, allowing clinical systems to connect to other systems in the public and private sector. The National Healthcare Safety Network is an example of a federal response to patient safety, including the CDC, Agency for Healthcare Research and Quality (AHRQ), the Center for Medicare and Medicaid Services (CMS), and the Food and Drug Administration (FDA).

The National Healthcare Safety Network (NHSN) is a knowledge system for accumulating, exchanging and integrating relevant information on infectious and noninfectious adverse events associated with healthcare delivery. The NHSN allows entry (manual and electronic) of event and summary (denominator) data for each data-reporting module in the network. The data analysis features of the network range from simple reports and graphs to statistical analysis that compares

the healthcare facility's rates with national performance measures.

The vision is to create a secure web-based reporting and knowledge system that will collect, exchange, and integrate pertinent information and resources among private and public stakeholders that support local efforts to ensure patient and healthcare worker safety. NHSN is a voluntary and confidential system derived through the integration of three existing CDC surveillance systems:

- Dialysis Surveillance Network (DSN): a voluntary surveillance system set-up in 1999 to assist hemodialysis centers in tracking and monitoring infections in hemodialysis patients. Information gathered through the network is used to compare rates between participating centers.
- National Nosocomial Infections Surveillance System (NNIS): The system is conducted by Hospital Infections Program to collect nosocomial infection data that can be combined into a national database.
- National Surveillance System for Health Care Workers (NaSH): the system supports the systemic compilation of data essential in preventing occupational exposure and infection among health care workers.

Data from such systems (NNIS, DSN, NaSH) typically are used as a benchmarking tool for this new network will eventually generate much more comparative data

than are currently available. (Source: www.cdc.gov/ncidod/hip/NNIS/members/nhsnsysreq.htm)

❑ Environmental Public Health Tracking Network

The environment plays an important role in human development and health. Researchers have linked exposures to some environmental hazards with specific diseases. One example is the link between exposure to asbestos and lung cancer. Another example is the link between exposure to lead and decreased mental function in children. However, other links remain unproven, such as the suspected link between exposure to disinfectant byproducts (for example, chlorine from showerheads) and bladder cancer.

In 1988, in its report, *The Future of Public Health*, the Institute of Medicine noted that the removal of environmental health authority from public health agencies has led to fragmented responsibility, lack of coordination, and inadequate attention to the health dimensions of environmental problems.

In January 2001, the Pew Environmental Health Commission issued the report, *America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*. The report, which stated that the existing environmental health system is neither adequate nor well organized, recommended the creation of a "Nationwide Health Tracking Network for disease and exposures."

Currently, there is limited ability at the federal, state, or local levels to track many of the exposures and health

effects that may be related to environmental hazards. In addition, in most cases, existing environmental hazard, exposure, and disease tracking systems are not linked together. Because existing systems are not linked, it is difficult to study and monitor relationships among hazards, exposures, and health effects.

CDC's goal for the Environmental Public Health Tracking Network is to develop a tracking system that integrates data about environmental hazards and exposures with data about diseases that are possibly linked to the environment. This system will allow federal, state, and local agencies, and others to do the following:

- monitor and distribute information about environmental hazards and disease trends
- advance research on possible linkages between environmental hazards and disease
- develop, implement, and evaluate regulatory and public health actions to prevent or control environment-related diseases.

In fiscal year 2002, CDC began to develop a nationwide environmental public health network and to develop capacity in environmental health within state and local health departments.

❑ Data Standards

Data standards serve as the foundation for both NEDSS and PHIN. Standard data organizations (SDOs) develop data standards, also called specifications or protocols,

for specific healthcare domains such as pharmacy, dental, laboratory, or insurance transactions. These standards enable a multitude of healthcare entities to exchange comparable sets of clinical and administrative data. Health Level Seven (HL7), SNOMED, and Logical Observation Identifiers Names and Codes (LOINC) are examples of data standards adopted by NEDSS and PHIN.

Health Level Seven (HL7) is one of several ANSI-accredited Standards Developing Organizations (SDOs) operating in the healthcare arena. Health Level Seven's domain is clinical and administrative data. HL7's mission is to: *"To provide standards for the exchange, management and integration of data that support clinical patient care and the management, delivery and evaluation of healthcare services. Specifically, to create flexible, cost effective approaches, standards, guidelines, methodologies, and related services for interoperability between healthcare information systems."*

SNOMED CT provides a common language that makes health care information accessible and usable, whenever and wherever it is needed, to improve health care across primary and specialty medicine settings internationally. Users apply SNOMED CT in a myriad of ways to meet their specific needs, including electronic health records, structuring data repositories, clinical benchmarking, outcomes assessment and disease registries.

The **LOINC®** laboratory terms set provides a standard set of universal names and codes for identifying individual laboratory and clinical results.

Communications and Learning Management

□ Epidemic Information Exchange (Epi-X)

Since its inception in December 2000, the Epidemic Information Exchange (Epi-X) has become the nation's only source of up-to-the-minute health information that is both protected and available to public health professionals nationwide. Epi-X brings together the collective expertise and surveillance capabilities of public health officials from every state in a single powerful tool designed to inform decision makers and public health professionals of the latest epidemiologic developments. Epi-X users are among the most respected and senior public health experts in the United States, and include State Health Officers, State Epidemiologists, State Public Health Laboratory Directors, State Public Health Veterinarians, and State Bioterrorism Coordinators. All Epidemic Intelligence Service Officers (EISOs) and key CDC personnel are also Epi-X users.

Epi-X users have exclusive access to critical reports about smallpox vaccination adverse events, recently reported cases of severe acute respiratory syndrome (SARS), and other ongoing concerns of vital interest and importance, such as West Nile Virus. During these challenging times, it is critically important to ensure that scientists and epidemiologists from the Centers for Disease Control and Prevention (CDC) and state and local health departments are free to communicate efficiently and rapidly with each other. Epi-X, CDC's secure communications network, was created specifically to meet this need and to create a mechanism for communicating time-sensitive public health

information. A component part of this process involves active notification of state and local public health officials during multi-jurisdictional or critical public health-related events.

Today, Epi-X has positioned itself as a powerful tool to help key public health officials prepare for and rapidly respond to events involving biological or chemical attack or other public health emergency, wherever and whenever they might occur.

□ Health Alert Network (HAN)

The Health Alert Network Program is a joint Local/State/Federal initiative to build a nationwide network of strong public health agencies to serve as the nation's frontline of defense against terrorism and other public health threats. The overall goal of the program is to strengthen capacity of health departments to serve as an early warning and response system for the nation. As an essential, integral component of the PHIN, the Health Alert Network Program will help to ensure that health departments have rapid and timely access to emerging health information, new knowledge for frontline professionals, and can effectively use and translate data and information into effective health action.

The Health Alert Network Program is being implemented in phases, designed to meet the most critical needs of public health departments.

❑ Learning Management Systems

An important aspect of the PHIN is integrating learning management systems with existing personnel directories and workforce development efforts. Roles, responsibilities, and standards are being defined for learning management systems in the PHIN.

❑ Laboratory Information Management Systems (LIMS)

Public health laboratories are critical to the functions of the Public Health Information Network (PHIN), from detection, monitoring, alerting to communicating and responding on disease outbreaks and other health threats. It is the responsibility of public health laboratories to identify and confirm disease agents and to collaborate with public health agencies, law enforcement organizations and others to ensure that this data is promptly and effectively utilized. Laboratories are thus an integral part of the response team during a public health crisis.

Since data, both clinical and environmental, is the chief output of laboratories, automated systems for its capture, analysis and exchange have become top priorities for public health laboratories across the country. A complete laboratory information management (LIM) system stands alone as unit for managing receipt, processing and dissemination of health data as well as managing other laboratory business processes, such as chain of custody, billing and quality control/quality assurance. All information in the system is automatically linked to the specimens and samples received and it is this data that

needs to be automatically exchanged with other information systems.

Currently public health laboratories are at an important juncture. They must either enhance or implement their LIM systems in order to meet PHIN specifications for “automated exchange of data between public health partners.” This technically requires the LIM system to be able to securely create/send and accept/translate electronic HL-7 messages using LOINC, SNOMED, ICD and IPC codes. LOINC and SNOMED are specific codes related to laboratory tests and results, whereas ICD and IPC codes relate to clinical descriptions. Ease of data exchange also requires determination of data needs and compatible formats.

Thanks to PHIN, public health agencies can now work collectively using information technology. However, rapid and accurate data exchange and robust data capacity will continue to be priorities for public health laboratories, particularly given terrorist threats and the presence of emerging infectious diseases such as SARS.

PHIN Progress

PHIN functions, specifications and standards have been required as part of CDC/HRSA extramural BT programs. These have also been adopted by state partners and now adopted for all CDC systems and initiatives. Specifications have been developed for the following IT functions:

1. **The Automated Exchange of Data Between Public Health Partners** - To securely and automatically exchange information, as appropriate, between two computer systems to achieve a “live” network for data exchange between partners in public health
2. **The Use of Electronic Clinical Data for Event Detection** -To receive, manage and process electronic data from care systems at clinical care sites, laboratories, or their proxies
3. **Manual Data Entry for Event Detection and Management** - To accumulate, manage and process information manually entered via a web browser at a health agency or remote site
4. **Specimen and Lab Result Information Management and Exchange** - For laboratories involved in public health testing, to receive laboratory requests, accept specimen and sample data, manage these data and immediately report electronic results to public health partners
5. **Management of Possible Case, Contacts and Threat Data** - To electronically manage, link and process the different types of data (possible cases from detection, possible contacts, facility, lab results, prophylaxis and/or vaccination, adverse events monitoring and follow-up)
6. **Analysis and Visualization** - To analyze, display, report and map accumulated data and share data and technologies for analysis and visualization with other public health partners
7. **Directories of Public Health and Clinical Personnel** - To participate in and maintain directories of public health

participants (including primary clinical personnel), including participant roles and contact information

8. **Public Health Information Dissemination and Alerting** - To receive, manage and disseminate alerts, protocols, procedures and other information for public health workers, primary care providers, and public health partners in emergency response
9. **IT Security and Critical Infrastructure Protection** - To ensure that sensitive or critical electronic information and systems are not lost, destroyed, misappropriated or corrupted

In addition, a messaging transport system based on industry standards for inter-institutional data exchange is available from CDC that provides secure exchange of real-time data across the Internet. The use of ebXML “handshake” technology, PKI encryption and security is an integral part of the messaging system, which can transport HL7 messages, but also can transport other content.

The NEDSS Base System version 1 is beginning deployment to 20 States. Features include a public health “in-box” for electronic messages, implementation of PHIN standards for messaging, directory, architecture, and data model. Version 1 enables receipt of electronic data from labs and the clinical sector, and supports investigation of 95 diseases.

Technical assistance and direct assistance is available for public health partners.

Benefits of PHIN

The current public health cycle (from recognition of a clinical event to response by public health authorities) is too long. The new realities of terrorism and emerging infectious disease require a new level of operation. PHIN offers an opportunity to shorten this cycle through electronic support of many public health functions. When fully operational, PHIN envisions a wide variety of functions:

- Supporting disease and threat surveillance
- Analyzing real-time data
- Transmitting emergency alerts
- Providing reference information, distance learning, and decision support
- Hosting professional discussions and collaborative activities

PHIN offers us the ability to analyze, understand, and make improvements to the public health system through enhanced information and knowledge. The use of common data standards adopted under PHIN will allow the various partners in the public health system to share information electronically and avoid exchanging information manually. PHIN can also help us simplify web of information exchange and reduce reporting burden.

An interoperable network would both improve the speed and quality of decision-making and reduce data entry costs. Public health information related to a person that originated from a variety of programs could be

accessible securely to appropriately authorized public health personnel in a single system and distributed in a timely manner. An integrated system could also reduce redundant data entry, resulting in cost savings. A single system could provide the different information needed for Local, State, and Federal programs.

Electronic communication between the clinical and public health sectors offers great promise. When health care providers and clinical laboratories are included in the information network, information will flow from the clinical setting to public health agencies in a faster, more complete, and more accurate manner. For example, the results of a blood test for lead would be available in hours to days rather than weeks to months, allowing more timely intervention by the health department.

An integrated system would also speed response by making the address and phone number of the patient's health care provider immediately available. Additional promise comes from the ability of the public health department to provide immediate feedback to medical care providers. Clinical systems are not currently interoperable, so obtaining broad clinical data is a worthy, yet complex, goal. Real-time monitoring of clinical and laboratory data would permit public health agencies to detect suspicious patterns of illness and provide background information and clinical practice guidelines to medical care providers.

Where Do We Go From Here?

Public Health involves many organizations working together and exchanging information. For the PHIN to be successful, public and private sector partners at the Federal, state, and local levels must work together to develop the requirements for the Network. Each stakeholder must be aware of existing agreed upon standards and goals as we develop new systems and improve existing systems, so that information can be easily exchanged.

There are a number of ways to support PHIN. One way is to participate in data standards development by working with the Public Health Data Standards Consortium at www.cdc.gov/nchs/otheract/phdsc/phdsc.htm and www.cdc.gov/cic/. Another is to make sure that partners are aware of PHIN standards when developing or enhancing information systems.

Who Are the PHIN Partners?

The PHIN Partners are a group of organizations that support CDC in its information exchange between states and local governments as well as other organizations. A list of the NEDSS Partner Organizations, the current NEDSS Partner Contacts, as well as the perspective and expertise that each can provide are listed below.

The **Centers for Disease Control and Prevention** is recognized as the lead federal agency for protecting the

health and safety of people - at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships. CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States.

Contacts: Claire Broome, Senior Advisor for Integrated Health Information Systems, cbroome@cdc.gov; John Loonsk, Associate Director for Informatics; and Tim Broadbent, Acting Deputy Director, Office of Integrated Information Systems, Office of the Director.

The **Association of Public Health Laboratories (APHL)** is dedicated to a healthier world through quality laboratory practice. The mission of APHL is to promote the role of public health laboratories in support of national and global objectives, and to promote policies and programs that assure continuous improvement in the quality of laboratory practices.

Contacts: Doug Drabkowski, Director of Program Development, ddrabkowski@aphl.org.

The **Association of State and Territorial Health Officials (ASTHO)** is the national nonprofit organization representing the state and territorial public health agencies of the United States, the U.S. Territories, and the District of Columbia. ASTHO's members, the chief health officials of these jurisdictions, are dedicated to formulating and influencing sound public health policy, and to assuring excellence in state-based public

health practice. The Informatics Program at ASTHO includes assistance to States and CDC for NEDSS, HAN, Epi-X, Knowledge Management, and HIPAA implementation. ASTHO works through an Informatics Policy Committee for much of its work in these areas.

Contacts: Mary Shaffran, Director of Informatics Policy, mshaffran@astho.org; Samata Kodollikar, Analyst for Informatics Policy, skodollikar@ASTHO.org.

The **Council of State and Territorial Epidemiologists (CSTE)**'s priority areas include the surveillance and epidemiology of infectious diseases, chronic diseases and conditions, and environmental health concerns. Over 150 members serve as special topic consultants for a broad range of public health concerns such as HIV/AIDS and vaccine-preventable diseases.

Contact: John Abellera, Associate Research Analyst, jabellera@cste.org.

The **National Association of County and City Health Officials (NACCHO)** is the national nonprofit organization representing local public health agencies (including city, county, metro, district, and Tribal agencies). NACCHO provides education, information, research, and technical assistance to local health departments and facilitates partnerships among local, state, and federal agencies in order to promote and strengthen public health.

Contacts: Carolyn Leep, Program Manager, cleep@naccho.org; Carol Brown, Senior Advisor, cbrown@naccho.org

The **National Association of Health Data Organizations (NAHDO)** is a not-for-profit membership organization dedicated to strengthening the nation's health information system. NAHDO serves as a broker of expertise for the development and enhancement of statewide and national health information systems. NAHDO brings together a network of state, federal, and private sector technical and policy leaders and consultants to expand health systems development and shape responsible health information policies.

Contacts: Alana Knudson-Buresh, Senior Health Informatics Analyst, aknudson-buresh@nahdo.org; Denise Love, Executive Director, dlove@nahdo.org.

The **National Association for Public Health Statistics and Information Systems (NAPHSIS)** is a Washington, DC-area based national association of state vital records and public health statistics offices. The association was formed in 1933 to provide a forum for the study, discussion, and solution of problems related to these programs in the respective members' health departments.

Contact: Maryam Mojarad, Director, Public Health and Informatics Projects, mmojarad@naphsis.org

The PHIN Partners' roles include:

1. Information Dissemination — Each NEDSS Partner uses their information dissemination tools to share information from CDC with members.

2. Information Feedback — PHIN Partners are an important conduit for CDC to take the "pulse" on members regarding progress, opportunities, challenges, new ideas, etc.

3. Special Projects — PHIN Partners collaborate on special projects that draw upon the expertise of each partner organization.

4. Conference Participation — PHIN Partners participate in conferences to share perspectives and gather information.

5. Information Exchange — PHIN Partners exchange information about members' projects.

6. Support PHIN Development — PHIN Partners participate in the development and implementation of PHIN by representing member needs and issues.

Additional Resources

CDC Web Sites

www.cdc.gov
www.cdc.gov/nedss

Partner Web Sites

Association of Public Health Laboratories (APHL)
www.aphl.org

Association of State and Territorial Health Officials (ASTHO)
www.astho.org

Council of State and Territorial Epidemiologists (CSTE)
www.cste.org

National Association of County and City Health Officials (NACCHO)
www.naccho.org

National Association of Health Data Organization (NAHDO)
www.nahdo.org

National Association for Public Health and Information Systems (NAPHSIS)
www.naphsis.org

Select Health Information Organizations

American Medical Informatics Association (AMIA)
www.amia.org

American Public Health Association (APHA)
www.apha.org

Association of Schools of Public Health (APHS)
www.aphs.org

Association of State and Territorial Directors of Health Promotion and Public Health Education (ASTDHPPHE)
www.astdhpphe.org

Medical Records Institute (MRI)
www.medrecinst.com

Select Standards Development

AdvaMed
www.himanet.com/index.shtml

American National Standards Institute (ANSI)
www.ansi.org

ANSI Healthcare Informatics Standards Board
<http://web.ansi.org>

CPRI-HOST Computer-Based Patient Records Institute
– Healthcare Open Systems Trial
www.himss.org/ASP/index.asp

Federal EDI Standards Management Coordination
Committee (FESMCC)
www.estrategy.gov/federal_edi_standards.cfm

Enterprise Business XML (ebXML)
www.ebxml.org

Health Level 7 (HL7)
www.hl7.org

Healthcare Information and Management Systems
Society (HIMSS)
www.himss.org/ASP/index.asp

National Institute on Standards and Technology
(formerly Bureau of Statistics)
www.nist.gov

Organization for the Advancement of Structured
Information Standards (OASIS)
www.oasis-open.org/home/index.php

World Wide Web Consortium (W3C)
www.w3.org

Workgroup for Electronic Data Interchange (WEDI)
www.wedi.org

Select Classification and Nomenclature Schemes

Current Procedural Technology (CPT)
www.ama-assn.org/ama/pub/category/3113.html

International Classification of Disease (ICD-9)
www.cdc.gov/nchs/about/major/dvs/icd9des.htm

Logical Observation Identifier Names and Codes
(LOINC)
www.loinc.org

Systemized Nomenclatures of Human and Veterinary
Medicine (SNOMED)
www.snomed.org

Unified Medical Language Systems (UMLS)
www.nlm.nih.gov/research/umls

Glossary of Terms and Acronyms:

- **American National Standards Institute (ANSI)**
A voluntary standards organization that serves as the coordinator for national standards in the United States and the U.S. member body to the International Organization for Standards. ANSI accredits standards committees and provides an open forum for interested parties to identify, plan and agree on standards; it does not itself develop standards. Standards are developed by Standards Development Organizations (SDOs).
- **Association.** In data modeling, an association is a structural relationship that specifies instances of one thing connected to instances of another.
- **Attribute.** In data modeling, an attribute refers to specific items of data that can be collected for a class.
- **Common Information for Public Health Electronic Reporting (CIPHER).** A set of standards and guidelines for data representation and code values which includes specifications for representing concepts as well as standard code lists for coded elements. The CIPHER standards can be linked directly to attributes in the Public Health Conceptual Data Model (PHCDM)
- **Class.** In data modeling, a class is a description of a set of objects that share the same attributes, relationships and semantics.
- **Data Model** A framework for the development of a new or enhances application. The purpose of data modeling is to develop an accurate model, or graphical representation, of the client's information needs and business process.
- **Datatype .** A specification of the allowed format for the values of an attribute. Examples include string, number, code and text.
- **Electronic Data Interchange (EDI).** A standard format for exchanging business data. An EDI message contains a string of data elements, each of which represents a singular fact, such as a price, product model number, and so forth, separated by delimiters (a character that identifies the beginning and end of a character string). The entire string is called a data segment. EDI is one form of e-commerce, which also includes e-mail and fax.
- **Electronic Lab-based Reporting (ELR).** ELR is the transmission of data of public health importance from clinical laboratories to public health agencies in electronic format. Ideally, data transmitted by ELR would be automated and would use standardized codes for tests and results allowing for timely and complete reporting.
- **Health Level 7 (HL7).** A standards development organization formed in 1987 to produce a standard for hospital information systems. HL7 received ANSI accreditation as an Accredited Standards Development Organization in 1994. The HL7 standard is an American National Standard for

electronic data exchange in health care that enables disparate computer applications to exchange key sets of clinical and administrative information. HL7 is primarily concerned with movement within institutions of orders; clinical observations and data, including test results, admission, transfer and discharge records, and charge and billing information (coordinating here with X12). HL7 is the selected standard for the interfacing of clinical data for most health care institutions.

- **HL7 Reference Information Model** A conceptual model that defines all the information from which the data content of HL7 messages is drawn
- **Health Insurance Portability and Accountability Act (HIPPA).** The Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996 are intended to reduce the costs and administrative burdens of health care by making possible the standardized, electronic transmission of many administrative and financial transactions that are currently carried out manually on paper.
- **International Organization for Standardization (ISO).** A worldwide federation of national standards bodies from some 100 countries, one from each country. Among the standards it fosters is Open Systems Interconnections (OSI), a universal reference model for communication protocols. Many countries have national standards organizations, such as the U.S. American National Standards Institute

(ANSI), that participate in and contribute to ISO standards development.

- **Lightweight Directory Access Protocol (LDAP),** is an Internet protocol that email programs use to look up contact information from a server.
- **Logical Observations, Identifiers, Names and Codes (LOINC).** The LOINC database provides a set of universal names and ID codes for identifying laboratory and clinical observations. The purpose is to facilitate the exchange and pooling of clinical laboratory results, such as blood hemoglobin or serum potassium, for clinical care, outcomes management, and research.
- **National Committee on Vital and Health Statistics (NCVHS).** External Advisory Committee to the Secretary of the Department of Health and Human Services (DHHS), and to the DHHS Data Council. Consists of 16 members with overlapping four-year terms. The National Center for Health Statistics (NCHS) serves as Executive Secretary. The NCVHS was established in 1949 in response to a recommendation by the World Health Organization (WHO). The committee was rechartered in January 1996 to include more direct focus on data standardization and privacy activities.
- **Process Model** A framework describing the activities, functions, and processes of an organization. Processes in a process model are often defined in terms of their inputs and outputs. Process models often accompany data models; a data model

does not reflect any action or flow of information and presents only a static view of data.

- **Public Health Conceptual Data Model (PHCDM).** A high level conceptual model, developed as part of the CDC NEDSS initiative, which provides the foundation for standardization of public health data collection, management, transmission, analysis and dissemination.
- **Secure Data Network Standards and Procedures (SDN).** Agency standards and operating procedures for the use of CDC/ATSDR Internet resources in the secure transmission and processing of sensitive or critical data and the support of sensitive or critical systems.
- **Subject Area.** A way of organizing classes into groups within a model, where classes are grouped together into higher-level units. Within the UML, a subject area is referred to as a package.
- **Subtype.** A specialization of another class, which inherits the attributes of its parent class.
- **Supertype.** A generalized class that is related to subtypes that inherit its attributes.
- **Systemized Nomenclature of Medicine (SNOMED).** A structured nomenclature and classification of the terminology used in human and veterinary medicine developed by the College of Pathologists and American Veterinary Medical

Association. Terms are applied to one of eleven independent systematized modules.

- **Unified Modeling Language (UML).** A graphical language for visualizing, specifying, constructing, and documenting the artifacts of a software-intensive system.
- **Unified Modeling Language System (UMLS).** Developed by the National Library of Medicine as a standard health vocabulary that enables cross-referencing to other terminology and classification systems. UMLS includes a meta-thesaurus, a semantic network, and an information sources map. Purpose is to help health professionals and researchers retrieve and integrate electronic biomedical information from a variety of sources, irrespective of the variations in the way similar concepts are expressed in different sources and classifications systems. Has incorporated most source vocabularies.
- **World Wide Web Consortium (W3C).** An industry consortium that seeks to promote standards for the evolution of the Web and interoperability between WWW products by producing specifications and reference software.
- **X12.** A standards development organization that develops uniform standards for inter-industry electronic interchange of business transactions - electronic data interchange (EDI). X12N, a subcommittee of X12, develops standards for healthcare insurance and claims processing.

- **eXtensible Markup Language (XML).** A specification developed by the World Wide Web Consortium. XML is designed especially for Web documents. It allows designers to create their own customized tags, enabling the definition, transmission, validation, and interpretation of data between applications and between organizations. XML provides a file format for representing data, a schema for describing data structure, and a mechanism for extending and annotating HTML with semantic information.